

Improving Hearing Services for People with Learning Disabilities

Participant Information Sheet

You are being invited to take part in a research study which aims to understand the challenges and barriers that people with learning disabilities face when they access Audiology (hearing) services or attempt to access hearing services. Before you decide to take part, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully before deciding whether to take part and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Thank you for taking the time to read this.

This project has been reviewed and approved by The University of Manchester Proportionate Research Ethics Committee.

Project Reference: 2021-12007-19165

About the research

➤ Who will conduct the research?

This project is being led by Dr. Siobhan Brennan at the University of Manchester. Siobhan is an Audiologist. Interviews will be carried out by Siobhan. All members of the research team are based in the Division of Human Communication, Development and Hearing at the University of Manchester. The project is being run in collaboration with Health Education England (South East Region).

➤ What is the purpose of the research?

The NHS have recognised that healthcare, including Audiology (hearing) services, need to be improved for people with learning disabilities. People with learning disabilities and autistic people are more likely to have undiagnosed and untreated hearing loss. If hearing loss is not identified

or addressed, this can impact on a person's quality of life, behaviour, and ability to communicate. This study aims to identify the challenges and barriers people with learning disabilities face when they access Audiology (hearing) services or try to access hearing services. The findings will be used to provide guidance and recommendations for Audiology services about how to improve their services.

You have been approached to take part in this study because you work in or with audiology services.

➤ **Will the outcomes of the research be published?**

We will share what we find out about the challenges of accessing Audiology (hearing) services with Health Education England, professional Audiology providers, and people with learning disabilities and their care providers. We will write journal articles and presentations for other academics and stakeholders who are interested in this area.

We will also share our findings on the study website: (<https://sites.manchester.ac.uk/aldap/>) and on social media. If you give your consent to take part, you can choose to receive a summary of what we found at the end of the project. The summary of the research findings will be provided in a format that is suitable for you.

➤ **Who has reviewed the research project?**

This project has been reviewed and approved by The University of Manchester Research Ethics Committee (Ref: 2021-12007-19165)

➤ **Who is funding the research project?**

This project is being funded by Health Education England, which is part of the NHS in England.

What would my involvement be?

➤ **What would I be asked to do if I took part?**

If you give consent to take part in the study, you will be asked to attend one interview which will take place online using Zoom videoconferencing. To take part, you will require access to a computer or other electronic device compatible with Zoom (such as a mobile phone or tablet/iPad), which is connected to the internet. If you need help to set up or use Zoom, please visit this website or ask the researchers: <https://www.autistica.org.uk/get-involved/get-involved-1-1/guide-to-webinars-on-zoom>.

Interviews will be held by Siobhan from the research team. Interviews will take up to 1 hour and will be audio-recorded (voice only). We will not record the video. The researcher will have their camera turned on in the interview so you will be able to see us. We would like to see you too, but if you are not comfortable, you can turn your camera off.

The researchers will either carry out the interview from their home or from the University of Manchester. They will ensure that nobody else is able to hear the conversation. The interview will take place on a date and time that is convenient for you.

During the interview, we will ask questions about your perspective of the barriers facing autistic people and individuals with learning disabilities in accessing and experiencing Audiology services. These are the main topics we will ask about:

Service structure

Barriers

Referrals

Professional confidence

Environment

Pathways

Communication

Audiological Investigations

You do not need to tell us anything you do not want to. We would encourage participants not to name specific audiologists or clinics, where possible. We will also remove all identifying information about hearing service providers from the final transcripts.

We will also ask you about materials that hearing services use to communicate with people with learning disabilities. For example, leaflets, emails, and online materials.

➤ **Benefits**

We want to provide a platform for professionals who work with autistic individuals and individuals with learning disabilities to express their views and opinions about hearing services. We will use these insights to make recommendations to Audiology staff for how they can improve their services. We hope that participants will find this a beneficial experience.

➤ **Will I be compensated for taking part?**

No.

➤ **What happens if I do not want to take part, or I change my mind?**

It is up to you to decide whether or not to take part. You should read this information sheet and then decide if you want to take part. If you want to take part, you can contact a member of the research team using the details on the final page of this document. If you do not want to take part, you do not need to contact us. If you do decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form or give witnessed verbal consent. If you decide to take part, you are still free to withdraw at any time without giving a reason and without any negative consequences to you.

We will audio-record (voice only) the interview so that we have an accurate record of what you say. Participants should be comfortable with being audio-recorded. It will not be possible to decline being audio-recorded but you will be able to leave the interview at any time and withdraw your data from the study.

Data Protection and Confidentiality

➤ **What information will you collect about me?**

In order to take part in this research study, we will need to collect information that could identify you. This is called 'personal identifiable information'. We will need to collect:

- Your name.
- Your email address and telephone number.
- An audio recording of the interview.

We will store all this personal information securely and we will not share personal information with anyone except the team at The University of Manchester. Audio-recordings will consist of a full audio recording of the interview. The researcher will say when the recording begins and ends.

➤ **Under what legal basis are you collecting this information?**

We are collecting and storing this personal identifiable information in accordance with UK data protection law which protect your rights. These state that we must have a legal basis (specific reason) for collecting your data. For this study, the specific reason is that it is "a public interest task" and "a process necessary for research purposes".

➤ **What are my rights in relation to the information you will collect about me?**

You have a number of rights under data protection law regarding your personal information. For example, you can request a copy of the information we hold about you, including audio recordings. This would be in the form of a transcript of the interview you took part in once all identifying information has been removed.

If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please see our [Privacy Notice for Research](https://documents.manchester.ac.uk/display.aspx?DocID=37095) (available at: <https://documents.manchester.ac.uk/display.aspx?DocID=37095>)

➤ **Will my participation in the study be confidential and my personal identifiable information be protected?**

In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means that we are responsible

for making sure your personal information is kept secure, confidential, and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following way:

- Only the study team at The University of Manchester will have access to your personal information, and they will anonymise it as soon as possible. Your name and any other identifying information will be removed and replaced with an identifier which will be anonymous. Only the study team will have access to the key that links this identifier to your personal information. Your consent form will be retained for 5 years after the completion of the project. These will be stored online in the University of Manchester's Research Data Storage (RDS) system, within a password-protected folder, which can only be accessed by the research team.
- Identifiable information, such as names of people and services, will be anonymised in the transcripts. This will ensure that it is not possible to identify you in the reported outcomes of the study.
- Your participation in the interview will be audio-recorded using Zoom and your personal data will be processed by Zoom. This may mean that your personal data is transferred to a country outside of the European Economic Area, some of which have not yet been determined by the United Kingdom to have an adequate level of data protection. Appropriate legal mechanisms to ensure these transfers are compliant with the Data Protection Act 2018 and the UK General Data Protection Regulation are in place. The recordings will be removed from the above third-party platform and stored on the University of Manchester secure Research Data Storage (RDS) system for 5 years, according to the University's Retention Schedule. This will be completed as soon as possible after the interview has taken place. The Zoom privacy notice is available at: <https://zoom.us/privacy>.
- The audio-recordings will be written up digitally (transcribed) for the purposes of analysis. Transcription will be completed automatically, using Nvivo. These transcripts will be checked against the audio-recordings by the researcher. This will be done in a private environment using headphones so only the transcriber will be able to hear the interview conversation. Personal identifying information will be removed from the final transcript. Transcripts will be stored on the

University of Manchester's Research Data Storage (RDS) system within a password-protected folder, which can only be accessed by the research team.

- If you decide to take part and would like a summary of the research findings to be emailed to you, you can consent to your email being stored for this purpose. Email addresses will be stored securely on the University of Manchester Research Drive in a password-protected folder. Otherwise, participant email addresses will be deleted once the interviews are finished. There will be no more contact after this point.

➤ **Potential disclosures:**

- If, during the study, we have concerns about your safety or the safety of others, we will have to inform your GP, care team or a family member.
- Individuals from the University of Manchester or other regulatory authorities may need to review the study information for auditing and monitoring purposes, or in the event of an incident. This may involve looking at identifiable data. All individuals involved in auditing and monitoring the study will have a strict duty of confidentiality to you as a research participant.

What if I have a complaint?

If you wish to complain or have any concerns about any aspects of this study or the way you have been approached or treated during the course of this research, please contact Siobhan Brennan (Project Lead) using the contact details below.

➤ **Contact details for complaints:**

If you have a complaint that you wish to direct to members of the research team, please contact:

SIOBHAN BRENNAN

Tel: 07917605544

Email: SIOBHAN.BRENNAN@MANCHESTER.AC.UK

If you wish to make a formal complaint to someone outside of the research team, or if you are not satisfied with the response you have gained from the researchers in the first instance, then please contact:

The Research Ethics Manager, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: research.complaints@manchester.ac.uk or by telephoning 0161 306 8089.

If you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to The Information Governance Office, Christie Building, The University of Manchester, Oxford Road, M13 9PL at the University and we will guide you through the process of exercising your rights.

You also have a right to complain to the [Information Commissioner's Office about complaints relating to your personal identifiable information \(available at: https://ico.org.uk/make-a-complaint/\)](https://ico.org.uk/make-a-complaint/). Telephone: 0303 123 1113.

Contact Details

If you have any queries about the study or if you are interested in taking part then please contact the researcher(s):

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You can also find information about the study on the study website:
(<https://sites.manchester.ac.uk/aldap/>).